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Demographic and social statistics: Washington Group on Disability Measurement

Report of the Washington Group on Disability Measurement

Note by the Secretary-General

The Secretary-General has the honour to transmit to the Statistical Commission the report of the Washington Group on Disability Measurement. The Commission may wish to:

(a) Review the objectives and work programme of the Group;

(b) Comment on whether its proposed work programme is attainable.

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Report of the Washington Group on Disability Measurement

I. Introduction

1. The International Seminar on the Measurement of Disability was held in New York from 4 to 6 June 2001. The Seminar, which brought together about 100 persons from developed and developing countries, was sponsored by the United Nations Statistics Division, the United Nations Children's Fund, the Statistical Office of the European Communities and the Centers for Disease Control and Prevention of the United States of America. Participants included statisticians from national statistical offices, representatives of the disability community, users of disability data, experts in the field of disability statistics, methodologists and representatives of the World Health Organization and other health organizations. The meeting participants, who represented a broad array of developed and developing country experts in disability measurement for statistical reporting, focused on:

(a) Reviewing and assessing the current status of methods used in population-based data-collection activities to measure disability in national statistical systems, with particular emphasis on questionnaire design;

(b) Developing recommendations and priorities to advance work on the measurement of disability;

(c) Contributing to building a network of institutions and experts, including producers and users of disability statistics, to implement the development of the field of disability measurement.

2. The programme, which included introductory remarks from the Under-Secretary-General for Economic and Social Affairs of the United Nations Secretariat, the Director of the United Nations Statistics Division and the Director of the Division for Social Policy and Development of the Secretariat, covered many important topics related to measurement of disability. Highlights of the programme were national experience in the development of instruments for measuring disability; international initiatives in the measurement of disability and techniques to improve analysis of data; the implications of the International Classification of Functioning, Disability and Health (ICF) for the measurement of disability, particularly the new elements focusing on environment and participation; and discussions of questionnaire design and survey features. Another important element of the seminar was the focus on the measurement of disability among special populations, such as children and those with cognitive or psychological impairments.

II. Seminar recommendations

3. Seven priority areas were identified for further work to improve the measurement of disability, and it was agreed that a city group be established to implement the recommendations of the seminar. The National Center for Health Statistics (NCHS) of the Centers for Disease Control agreed to host the first meeting, which will take place in Washington, D.C.

4. The recommendations of the Seminar included the following:

(a) That ICF be used as the framework for measurement of disability in future work. Short and long sets of questions for data collection should be developed based on ICF. Particular attention is needed in the development of instruments to measure the new ICF elements of environment and participation;

(b) That global measures and instruments be developed for use in censuses and surveys that do not focus primarily on disability;

(c) That assessment of the impact of cut points and multi-point response scales on the measurement of disability, including use of ICF qualifiers with relationship to difficulty, assistance, extent, satisfaction etc., are important methodological issues to be addressed;

(d) That emphasis be placed on improving the comparability of disability data cross-nationally, while being sensitive to the cultural and resource differences encountered in different countries, including the harmonization of concepts and definitions, the development of a core set of reference items and the use of statistical techniques, such as item response theory;

(e) That attention be paid to the development of instruments and issues associated with measuring disability among special populations, such as children, the elderly, institutionalized populations, and persons with cognitive and psychological impairments;

(f) That the impact of question design on estimates of persons with disabilities be studied, including methodological issues of self versus proxy respondents, household versus person-based questions, multi-point scale cut points, negative terminology etc.;

(g) That collaboration on disability data topics be enhanced by including stakeholders and data users, developing working relationships and networks among countries, and exchanging information and establishing guidelines for the use of data.

III. Planning committee

5. The United Nations Statistics Division suggested members for a committee to plan the first meeting of the Washington Group on Disability Measurement, including:

Antonio Escobedo Aguirre, Instituto Nacional de Estadistica Geografia e Informatica (Mexico)

Ms. Ssekabira, Ministry of Gender, Labour and Social Development (Elderly and Disability Affairs) (Uganda)

Marleen de Smedt, Statistics on Health and Safety, Statistical Office of the European Communities

Joanne Hillermann, Australian Bureau of Statistics

Ken Black, Australian Bureau of Statistics

Ros Madden, Australian Institute of Health and Welfare

Jennifer Madans, National Center for Health Statistics (United States)

6. In addition to Ms. Madans, the following NCHS staff are supporting the planning committee: Barbara Altman, Linda Blankenbaker, Dana Carr, Marjorie Greenberg, Sam Notzon, Paul Placek, Beth Rasch and Diane Shinberg. Logistic support is being provided by Pat Drummond and Barbara Hetzler.

7. The United Nations Statistics Division is represented in the Group by Margaret Mbogoni (focal point) and Angela Me, and the World Health Organization by Bedirhan Ustun.

8. The Group began planning its activities in late August 2001. Through email correspondence and telephone calls, the planning committee has developed a set of tentative objectives for the Group and a draft agenda for three proposed meetings, with a more detailed draft agenda for the first meeting, to be held in Washington, D.C., from 18 to 20 February 2002 (see annex).

IV. Objectives of the Group

9. The planning committee has proposed the following as draft objectives for the Group, subject to amendment and approval by Group members when they meet in February 2002. Adequate time will be set aside at the meeting to discuss the objectives and agenda for the Group.

10. The objectives as currently proposed are as follows:

(a) Recommend principles to guide the development of global measures of disability, for use in a census format, that are culturally compatible and will provide the basic necessary information on disability throughout the world;

(b) Recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components in population surveys or as supplements to specialty surveys. Such principles for developing questions should be representative of the ICF model and culturally comparable. Modular components can be conceptualized so that they may be combined to encompass the body/structure, activity/participation and environmental components of disability, where possible;

(c) Address the methodological issues associated with measurement of disability considered most pressing by the participants.

11. In order to meet those objectives it will be necessary to:

(a) Review and assess cross-cultural differences in disability definitions, the purposes of collecting disability information and barriers to the collection of accurate disability data, as a step in promoting the comparability and usefulness of disability data collected either through censuses or surveys;

(b) Review the sets of global measures used in censuses and survey measures currently in use or

proposed in participating countries, developing the underlying principles that indicate successful measurement;

(c) Evaluate methodological problems in developing measures, particularly in the new areas of measurement of participation and environment, as well as in the measurement of special populations in order to promote the development of culturally compatible measures in those areas.

12. In addition, it will be necessary to continue building a network of institutions and experts, including producers and users of disability statistics, in order to implement the development of the field of disability measurement so that data-collection instruments will be put to use to produce the information needed.

Annex

Provisional agenda/programme of work for the first meeting of the Washington Group on Disability Measurement

Topic: Comparability of cross-national disability measures

Day 1

Morning

1. Introduction and overview

Presentations will be made on the current situation of disability measurement, providing (a) a welcome to participants, (b) a review of the conclusions of the International Seminar on the Measurement of Disability, (c) setting the goals for the meetings of the Washington Group on Disability Measurement.

2. Goal-setting and agenda adjustment

Participants will be asked to approve or modify the proposed goals, and to adjust or make suggestions for additional topics to be addressed in subsequent meetings.

Afternoon

3. Purpose of measurement

Select participants, representing both developed and developing countries, will identify the purposes for disability measurement in their societies and relate them to the conceptual components of the ICF model. This will represent the type of conceptual operationalization that will need to be examined and decided upon in the work that follows.

4. Discussion of the Principles and Recommendations for Population and Housing Censuses, Revision 1, section on disability (paras. 2.258-2.276)

The Group will review the concepts, definitions and classifications of disability, as well as the recommended approach to collecting data on disability in the census recommendations, and will make revisions to them based on ICF. In addition, it will discuss the process that will monitor the implementation of those recommendations.

5. An examination of the ICF model

The Group will be updated on the status of the development of questions to create measures in each of the domains of the model. An inventory of existing instruments available will be provided as a background document, and the Group will discuss how selected instruments are reflecting the ICF model.

Evening

Reception or dinner

Day 2

Morning

6. Global measures of Disability

The Group will discuss the types and numbers of questions that could usefully be used in census formats. Of particular concern would be the impact of the cut point associated with limited questions on the estimates of disability that would result.

7. Exploring the confounding function of assistive device use

The Group will explore the identification of disability and whether the lack of specification of assistive device use alters a true count of what is happening within a population. Does the lack of accurate consideration of all devices and their use compromise our measures? How does that affect global indicators?

Afternoon

8. What is the relationship of global measures to ICF?

The Group will examine what components of ICF are most useful for measuring disability in a more global context with limited questions. Are global measures of environment and participation possible? Are measures for separate populations possible in a census context?

9. What are the unique cultural practices that influence the nature of the environment or prescribe or proscribe participation?

To ask participation questions in a culture that prohibits certain types of participation to certain members of the population is an exercise in futility. Presentations should address the cultural attitudes within which the questions must be framed. Does this problem constitute a barrier to collecting comparable data?

10. What are the unique cultural issues that act as barriers to collecting data? are there common barriers to data collection that occur cross-culturally? Possible topics include stigmatization and language barriers in multi-language cultures. How common are these across different cultures? A presentation could be made on the ways to involve persons with disabilities in the planning process and what is necessary to allow for their full participation.

Evening

Unscheduled activities

Day 3

Morning

11. Discussion of the comparability of information cross-nationally

Using materials from the previous day, the Group will split into two or more subgroups for a discussion of the comparability of the definitions, formats and forms of data collections. How well do the global indicators serve the purposes of various countries? The objective would be to identify the areas of greatest differences and possible solutions to those differences. In addition, another purpose of this exercise

would be to create working groups that might possibly form alliances that would continue to work after the Group had completed its work. Obviously, Eurostat has accomplished this, but many of the developing countries could probably use this networking opportunity. Subgroups will return at mid-morning to report their findings and discuss the nature of the most difficult differences. This will also provide an opportunity to develop further agenda items for subsequent meetings.

12. Cross-cultural validity of global indicators

Can we agree on what specific global indicator or set of global indicators is workable?

Afternoon

13. Conclusion

To facilitate discussion, representatives of participating countries will be asked to send a description of the sources of data used to gather information on disability, and also to describe how the information is used in their cultures based on guidelines set out by the planning committee. In addition, each participating country will be asked to indicate the legal definitions of disability in place in their societies. Both pieces of information will be collected prior to the concluding meeting for distribution at that meeting, and will be used to facilitate the discussion of compatibility.

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Possible future topic areas

The following are possible future topic areas:

Sampling issues

Self versus proxy respondents

Question design

- Terminology
- Response options
- Use of qualifiers

Building blocks: can questions be developed in add-on components that will allow expansion or contraction of disability unit as resources and space allow?

Measurement error

Scales

Statistical techniques to promote comparisons

Status of environmental and participation measures

Successful supplements in use and their problems

Incorporation of institutionalized populations in prevalence estimates

Measurement of disability among children, adolescents and elderly

- Problems associated with various age groups
- Self/proxy issues
- Cognitive limitations
- Mental health problems

Psychological and cognitive impairments

- Special cultural barriers to data collection

Uses of data

- Constructive use of disability in overall health measures
- Data users' needs: policy considerations